Deliberative Scenario: Law Enforcement Access to a University's Genetic Database

Dear Academia University Members:

Thank you so much for agreeing to serve on this special purpose committee to assess a law enforcement request for access to the university's genetic database.

As you know, Academia County was recently devastated by a shocking murder in close proximity to the University. Law enforcement was able to obtain a DNA sample from the crime scene that is believed to have come from the alleged perpetrator. The DNA sample was run through the local and national law enforcement databases, but the sample did not match any of the existing profiles. Law enforcement has therefore requested access to the University's extensive genetic database developed primarily for biomedical research that is conducted on campus.

As you know, individuals who have agreed to share their DNA samples with University researchers have signed an informed consent document. The informed consent process is designed to provide information that allows individuals to make an informed decision about, among other things, the consequences of agreeing to participate. The relevant portions of the University's informed consent document are excerpted below.

In your consideration of this request from law enforcement, please think about the broader implications of granting or denying access to the University's genetic database. Please develop a policy that can be used to respond to this and future requests from law enforcement.

Sincerely,

Dr. J. Wilson
Associate Dean for Research

Academia University's Informed Consent Policy

The following provisions detail Academia University's approach to the confidentiality of genetic samples stored in the Academia University database.

Confidentiality

A code number will be assigned to your DNA sample. Any link between the code number and your identity could be

(Cont.)

accessible to a few authorized personnel who have agreed to maintain the confidentiality and security of this information. The coded samples will be stored securely for an unlimited period of time for subsequent research use.

Your genetic sample will be made available to Academia University researchers and other qualified researchers. Only the coded sample will be provided, and traditional identifiers (e.g., name, birth date, social security number) will be removed from the shared sample.

Identifying information will not be revealed in any publication of study results. Researchers can, however, take steps to prevent serious harm to you or to others in the community; these steps may include, but are not limited to, reporting information to the authorities.

In spite of all of the safety measures that we at Academia University use, we cannot guarantee that your identity will remain forever confidential. For example, we cannot predict the ways that technology will evolve that permits identities to be derived from the genetic sample alone. It is also possible that information from your biologically-linked family members could be used to identify you, or that your information could be used to identify biologically-linked family members.

To address this problem comprehensively, you have broadened the group to include institutional review board members, members of the genetic database governance board, students, research participants, researchers, university lawyers, law enforcement officers, university administrators, and other stakeholders relevant to the decision making process.

Please come to the deliberation having read the following pieces of background information:

- "Guide to Classroom Deliberation for Students and Teachers"
- Hayden, E.C. (2012, June 20). Informed consent: A broken contract. *Nature*. Retrieved April 19, 2016 from http://www.nature.com/news/informed-consent-a-broken-contract-1.10862.
- Presidential Commission for the Study of Bioethical Issues (PCSBI). (2012, October). Privacy and Progress in Whole Genome Sequencing. Washington, DC: PCSBI, pp. 1-11. Available at: http://bioethics.gov/node/764.